

EDUCATING OLIVER

A CASE FOR SPECIAL TREATMENT 1982–2007

PHILLIP MEDHURST

WITH THE DOCUMENTS OF PHILLIP

– OLIVER MEDHURST'S FATHER –

EDITED WITH PERMISSION BY

HARRY KOSSUTH

IN TWO PARTS

PART 1: LEICESTERSHIRE. 1982–1985

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PART 1: LEICESTERSHIRE

Journal. 26 September 1982 [Sunday]

It will be six weeks on Tuesday since Oliver was run down by a car on the dual carriageway at the bottom of our street. He now appears to be growing stronger, and in purely physical terms the worst seems to be over. But there is much about Oliver's present state that is difficult to interpret, and this is one reason why I have decided to make notes on his progress. The other reasons, I am sure, will become apparent as this journal progresses.

The exact circumstances of my son's accident have not been ascertained and probably never will be. Among the plethora of fickle testimonies painstakingly compiled by the police, and which, in view of their superfluity in legal terms I have declined to read, my wife and I have alighted on one. My wife could probably recount the details of which shopkeeper or eagle-eyed neighbour originally communicated this narrative, but whether observation or surmise, it is the version which rings true to me.

According to this, Oliver, no doubt in his habitual state of athletic excitability and boyish urgency, was at the pelican crossing having fulfilled his errand of buying a cake. It being summer holiday time, Jackie, myself, grandpa and Oliver had just shared a fish and chip lunch at my father's house. Having improvised the first course, we agreed to improvise the second, and sent Oliver on his five minute journey to the local shops. My last memory of him before the catastrophe sees him seated at the dining-table, his peaked cap [a present from Holland] pulled determinedly over his temples, methodically devouring the rough-and-ready delicacy. He was clearly pleased to be part of this intimate and exclusively adult family circle [his sister being elsewhere], gleefully tolerating the turgidity of adult conversation in exchange for inclusion as we discussed the logistics of conveying Rebekah to and from her new school.

What happened to him after he received his instructions and departed on his errand [a chore so mundane that I hardly noticed his absence in my absorption with the daily paper] is partly a matter of speculation. It seems that, while waiting impatiently at the crossing, mission accomplished, a lady took her chance, ignored the signals, and crossed. Oliver followed her example. He was struck by a car. He broke both legs and sustained a serious head injury. A shopkeeper called an ambulance.

Meanwhile, my wife, concerned as to his whereabouts, had made a brief foray. Seeing the maelstrom of flashing lights, signalling uniforms and static pedestrians it registered instantly as the mother's nightmare.

Still absorbed in tabloid trivia like a sunbather on the edge of a crumbling precipice, I had no idea that the ring of the doorbell which drew me so unwillingly from my complacent lethargy was a summons to Hell. The child, Oliver's friend, said simply, "Oliver's been run over."

I wanted to cry out. Instead, I ran. I did not run at my fastest because that was to admit something unthinkable. The traffic had stopped on the opposite carriageway. I reached the crossing. Someone said "Here's his father." Ironically, I remember methodically pressing the signal button on the crossing and waiting patiently for the traffic to stop. An official of indeterminate uniform stepped forward to halt it. I crossed. Jackie stood weeping. Oliver was in the ambulance. We got in. Then followed the tumble into the abyss: the ambulance rocking and lurching as though tossed on the sea of Chaos; the gruesome rattle of the suction-tube; the intense glances and cryptic murmurs of the ambulance-men; the studied abandon of the driver. Oliver kicking, turning his head, rolling his eyes. The smudge and smear of blood. The paleness and trembling and uncomprehending stare of his mother. The clenching jaw Arriving at the Infirmary.

Journal. 3 October 1982 [Sunday]

Oliver was in intensive care for two weeks following an operation to deal with internal bleeding in the skull. The problem was to control pressure on the brain due to swelling. Treatment included heavy sedation and the use of a ventilator inserted via tracheotomy. After I.T.U. and successful control and reduction of pressure Oliver was passed on to a children's ward. Last week-end [ie. nearly one month after I.T.U.] he seemed to be on the road to improvement. While not "conscious" in the normal sense he was breathing for himself, he could move his hands, arms, head, toes, eyes and make sounds. He reacted to sound. This was encouraging even if he did not respond to verbal instructions. There seemed to be no paralysis apart from his right pupil which did not [and still does not] react to light. He was not "seeing" and "hearing" [as far as we can understand] in the normal sense, but the fact that he "jumped" at a sudden clatter encouraged us to play tapes. His increasing strength encouraged us to sit him up in bed [as far as the leg-plasters allowed] using our own bodies as support. While seated on the bed in this way it was difficult to see reaction since we were facing the same way, but observing Jackie in this posture with him last Sunday it seemed that he was reacting to affection. His arms were relaxed, as were the muscles round his mouth. When Jackie kissed him on the lips he opened his mouth as if for more; when I kissed him he curled his upper lip, clearly preferring his mother's scented embrace to my grizzled overtures. Things seemed to be moving.

Then, last Sunday night, we received a call from the hospital: Oliver was having breathing difficulties; he seemed to have an obstruction in his throat. The demon of anguished shock woke up with a vengeance; the ride to the hospital was like a nightmare recall of the ambulance terror. It was probably a fit. We had not anticipated setbacks. When the crisis passed, we were all left very low. But that dreary train of events is still being lived through, and its telling demands more energy than I have now

Journal. 4 October 1982 [Monday]

Now, as I write, Oliver is undergoing an operation. I have already mentioned the setback of last week. On that difficult night a nurse called Fiona, who seems to

have a special affection for Oliver, noticed that he was experiencing breathing difficulties. The nearest doctor to hand, an anaesthetist, was called into the ward. She knew nothing of him. He was given oxygen orally, his tracheotomy-pipe having been removed just over a week before. Just after we arrived Dr. O'C. came in, one of the doctors from I.T.U. He inserted an airway in his mouth. This has remained since that time. He speculated, since there was no obstruction and his chest was clear, that Oliver was having a fit, and prescribed an anti-epilepsy drug.

Gradually, the crisis subsided. I arranged for Jackie to be taken home and I stayed at the hospital that night. Eventually Oliver passed into a deep and tranquil sleep. Before this, however, I saw the tense spasmodic movement of the arms which, according to the night staff, had not been uncommon at night. It showed an aspect of Oliver's state which I had been completely unaware of. It seemed to open a trapdoor into the darkness of another storey of his damaged mind.

Throughout the following week he seemed very tired and his general level of awareness appeared to be in decline. The paediatrician, Dr. M., seemed puzzled and worried: Oliver's blood-pressure was high and was having to be controlled by drugs. Clearly, something was wrong inside Oliver's head, although we were pleased by his efforts to remove the nasal airway which had been inserted later on the difficult night, and the nasal-gastric tube by means of which he was being fed. This indicated, I believe, Oliver's basic problem. Under the impact of the hurt and shock, Oliver's mind [if I may use a word whose meaning I am not sure of] had retreated into some dark, closed void. Each new "therapeutic" procedure, aimed at relieving his physical state, seemed a jarring re-iteration of that first psychic shattering. Skull incisions, suctions, alien murmurs, arm incisions, throat insertions, encased legs anaesthetic bludgeons, the throb of swelling and cuts and sores and knitting, and the pain of the hurt that had forced its way deep inside his body's citadel and crashed into the watchtower of his being, all were the reiterated roars, jabs, and twists of the demon that was upon him.

Cradled in his mother's arm that Sunday the demon was, perhaps, slumbering, and Oliver was stirring as if to creep to the mouth of the lair, into the light and warmth which we longed to share with him. But something happened that night to drive him back to huddle in a corner of the cave. Maybe a fit, another callous blow from the demon's brutish arm, a warning cuff to stifle the lure of sunshine. Or perhaps Oliver's nerve failed him. Dr. M. does not seem to believe it was a fit, and appeared irritated by Dr. O'C.'s prescription of a perhaps top-heavy dose of the epilepsy drug. The demon if stunned, had pinned down his thrall beneath his dominant mass. No. Dr. M. thought that, venturing out, Oliver had turned to the support of his breathing tube, to find it gone. It was a momentary panic of the emerging psyche. Is it just a father's fancy to recall the breathless panic that I too have been experiencing these nights in the face of a deep and comfortless sleep, and to believe that this is just a shadow of the darkness that now envelopes my son, whose soul is linked to mine by silken threads that still twitch at the labyrinth's mouth?

I know and love Oliver. This enigma, this unresolved wonder of our familial love, deep down beyond the mere accidents of intelligence and perception, is: I know him. We will not part. Nothing, not even death, can divide us. My soul hurls a challenge to Chaos. Evil must vent its fury and spend itself; it knows it cannot win.

Throughout this time some continuing consultation had been going on with neurologists at Derby Royal Infirmary. Oliver was not getting better and something had to be done. No doubt on the evidence of the scans [no-one seemed to make much sense of an E.E.G.] Derby diagnosed a build-up of fluid. This could be relieved by inserting a tube internally to drain the fluid into some comparable cavity in his abdomen; my knowledge of anatomy is vague. This wondrous device may relieve his condition and lead to progress, or it might not. We shall see. I am not over-optimistic. While not ungrateful for the surgical techniques which have indeed saved Oliver's life and prevented God knows what suffering, I believe that the Problem is far more deep and complex than the surgeon's knife can solve, and it is not just Oliver's problem. It is a moral problem: coping with handicap. It is an emotional problem: channelling feeling into healing and creativity. It is an intellectual problem: how does the brain actually work? It is a problem of the re-ordering of priorities, the re-orientation of values: not just of the little world of Jackie and myself, but of the whole world, yes, even the cosmos. I dare to say that my own little family problem is indeed earth-shattering or the dawn of a new age in that spiritual sphere where human scale is unimportant. We shall see

Despite further violent, if benign, assaults on Oliver's physical integrity [an operation labelled with endearing simplicity as "the shunt"], surgery seems to have had an almost instant effect. Sitting here beside his bed, I see that his eyes are very slightly open with rapid to-and-fro movements. His hands are relaxed and his arms [particularly his left] are moving gently, although contracted at the elbow. His left leg moves spontaneously at intervals; earlier this afternoon he was moaning insistently. He now looks more bewildered than withdrawn. I guess that there is now some ground for cautious optimism.

Journal. 27 October 1982 [Wednesday]

On arrival [about 5.00 p.m.] I propped up Oliver against my chest with my left hand flattened against my chest. For about four minutes he emitted a series of moans including one load moan, almost a cry. [My father had clearly heard the same sound. Last Friday he claims that he shouted "Oi" when father was moving his head from side to side. On the same day nurses claim that he "shouted" when taken out of the bath.] Conclusion: this may be in response to unusual, though not necessarily unpleasant, sensations. It probably indicates and articulates objection, and may be a positive progression from the movements we witnessed before the ventricular-peritoneal shunt was inserted: bringing his hands to his face in a "cringeing"-type action. I believe it indicates a very basic attempt to relate to his environment through elementary communication.

We had not experienced any evidence of will or effort since his attempts at Derby to nudge out his naso-gastric tube. These attempts have since subsided, possibly because his nose is no longer sore after a clumsy insertion of an E.T. tube during his "fit". Today I tried shaking his left hand loosely at the wrist. After about six seconds on three consecutive tests he pulled his hand away. It was a weak action, but unmistakable. I fail to see how this can be interpreted simply as "reflex".

Journal. 3 November 1982 [Wednesday]

Having read a little about ontogeny, it appears that Oliver currently has the responses of a one-month-old baby. It is still open to question whether or not we could move him on towards the responses of a three-month-old child. It is unclear at this stage whether the handicaps are neurological or psychological.

My body is yours;
my brain is yours;
your soul is entrusted to me.

If Oliver's "problem" is psychological, then we must provide him with the comforts of the womb, while coaxing him towards birth. This is the prime aim of his mother. If his "problem" is neurological, then we must extend his brain, both as receptor and emitter, by means of electronics. This is the prime aim of his father.

Journal. 2 December 1982 [Thursday]

Oliver has made some small but encouraging progress over the last couple of weeks, the most rewarding of which is his new-found ability to smile. Although this does little to overcome his physical problems, it is a tremendous boost to morale. When it first happened [I was talking to him about his favourite foods] Jackie and I were together. This was great. If either of us had reported the "event" to the other, it would have been met with incredulity. As it was, it happened three times "on the trot": chocolate . . . smile and "coo"; ice cream . . . smile and "coo"; cake . . . smile and "coo". And yesterday, for the first time, he smiled at what he heard on tape [no doubt recognising John Pertwee as "Wurzel Gummidge"]. This is personality.

Much more important in medical terms is his growing ability to swallow. He began to take baby-food about three weeks ago, and now has two liquidised meals a day. Consequently, he is now physically a great deal more robust. The physiotherapists continue to spend a great deal of time with him, and have just started to take him out of the ward. They seem rather clandestine in their behaviour. Whether this is because they are jealous of their "trade secrets", or because they are trying something along the lines of "patterning" - establishing the correlative mental circuits appropriate to his next stage of development. At the moment it's difficult to establish a dialogue with the physio's: they operate in the early afternoon when I don't normally visit. But since everyone is now talking about a training or induction week for Jackie and myself at the hospital after Christmas [an introduction to some of the problems we might meet in

nursing Oliver at home], I guess there will be more fruitful contact with the physiotherapists then. I see them as the hospital's major input at the moment. Oliver is now not simply "not stiff": he is supple. It's good to see him tired in the evening. It must be a great aid to real healing sleep and a creative antidote to boredom and frustration.

We hope that we are on the threshold of some communication with Oliver. It seems [Jackie is more convinced than I am] that he will both blink and widen his eyes to instruction. Experimenting yesterday, he did seem to be doing this. The telling point is that when congratulated on his clear response to instructions, he smiled. This could be a major breakthrough. As far as we can see, he has no comparable control over any other part of his body, although there is a shade of co-operative movement in his arms. Dare we begin to think of a system of codes? Our biggest worry now is our future domestic arrangements. I hope the picture will become clearer in the next few days

Letter. 15 December 1982. To: Head of Special Education Section, County Hall, Leicester. [Mr. L.]

I am writing to you in connection with my son who is nominally a pupil at Belgrave C. of E. Primary School, Leicester.

Oliver sustained a serious head injury resulting in brain damage as a result of a road traffic accident last August. He is now undergoing treatment in Children's Ward 11 at the Leicester Royal Infirmary under the supervision of Dr. M. Domestic problems are being dealt with by Miss C. P., the Hospital Social Worker.

The competence and commitment of Mrs. V. P. [acting Headmistress] and her staff at the L.R.I. School are above question. Nevertheless, Oliver undoubtedly has special educational needs which they are not necessarily trained to meet. I would be very glad to initiate some discussion and consultation regarding any special provision which can or should be made for him both in the short- and long term.

Without wishing to pre-empt any decisions which may be imminent, you will appreciate my concern that there should be maximum co-operation with medical and social-work staff even at this early stage in order to achieve the optimal progress and quality of life in his present situation. I must stress again that I am in no way questioning the L.R.I. School's ability to make excellent provision for developmentally "normal" children. I would be delighted to discuss the matter with you at any time during normal working hours in the next three weeks.

Circular: Ten Discussion Points re. Special Educational Needs.

1. We feel that the question of educational provision for Oliver during the summer term should be sorted out as soon as possible, since other, fairly complex arrangements need to be structured around it. He will be returning home on the 28th March.
2. On the basis of visits already made, we are not convinced that there is any special school in the city which can adequately cater for Oliver's needs at this precise moment in time. We recognise that it may be impossible to achieve a perfect long-term solution given the accepted priorities in resource deployment, but in order to avoid possible disruption at a later stage we feel that the utmost care should be taken over deciding what is the most appropriate long-term provision. In view of this, placement may best be deferred until the beginning of the next academic year. Whatever the outcome of discussion, we may be eager to take advantage of our statutory right to comment on the draft of the statement of our son's needs together with other rights under the 1981 Education Act. We may also, if necessary wish to avail ourselves of the opportunity to view and comment upon any personal records appertaining to our child in accordance with the recent resolution of the Policy and Resources Committee.
3. Oliver's peak phase of alertness is during the morning session. Thereafter fatigue sets in. We feel, therefore, that any specific educational input needs to be concentrated in the morning. In view of this, school might not be the most appropriate provision at this stage. Pending further discussion we may be of the opinion that a home tutor should be made available for an adequate daily session for the remainder of this current academic year. This provision could be coupled with access for both tutor and tutee to the facilities of a "normal" school in the home locality in order to provide for social and other stimulation. This would be entirely appropriate to a post-Warnock situation.
4. While Oliver is now we feel certain, capable of sustained concentration during an entire morning session, it may be difficult for a teacher to sustain such a concentrated educational input on a one to one basis. Any one tutor would be in need of the support and guidance which teachers enjoy in a normal school situation. We feel, therefore, that the optimal provision would be two tutors, each employed in the two two-hour sessions in the morning, with a half-hour "cross-over"/liaison period in-between. During this half-hour period Oliver would have a break between the hour-and-a-half lessons on either side while the tutors were planning/conferring.
5. Any tutor should be guided by the Schools' Psychological Service in the formulation and resourcing of an individualised learning programme which may take into account the following factors:-
 6. [a] Oliver's hearing and aural comprehension is excellent;
 - [b] There are problems with Oliver's vision. His perception of colour is very good, but with unfamiliar visual stimuli there appears to be a delay of

some seconds in recognition. This should be borne in mind when using animated displays or scanning devices.

[c] Oliver is proficient in the use of eye-movement [upwards], head movement, and indeterminate sound.

7. A co-ordinated, multi-disciplinary approach to the question of input controls to a Possum-type system should be tackled at the earliest possible moment. It is imperative that a more-than-rudimentary system of communication should be developed as soon as possible if Oliver is to make real progress. We cannot accept a constant deferment of this challenge. A system should be used and developed which lends itself to progression to increasingly sophisticated levels. There therefore needs to be close co-operation between teachers, psychologists, physiotherapists, speech therapists and occupational therapists. Who can, and will, take responsibility for this?

8. We accept that there is a possibility that there may be some permanent impairment of Oliver's ability to talk. There is, however, such a thing as "self-fulfilling prophecy". In view of his relatively advanced capacity to understand language and the inevitable psychological factors involved we will not accept any pessimistic diagnosis until we are convinced that every conceivable initiative and creative technique has been attempted and sustained for an acceptable period by speech therapists. We are aware that during the last three weeks Oliver's capacity to make meaningful vocal response has accelerated.

9. We wish to acknowledge that a major educational contribution has already been made to Oliver's progress by physiotherapists at the L.R.I. Quite apart from his obvious physical requirements, we that regular, preferably daily physiotherapy should be an integral part of educational provision, and special attention should be paid to the question of what strategies Oliver can employ to control or modify his environment and to communicate if he is to make real progress as a total person.

10. The "blob principle" must be avoided at all costs, especially when it operates at unconscious levels. Neither should the difficulties involved be inflated by bureaucratic ineptitude, lack of professional commitment, or covert discrimination veiled by the complexity of essentially political questions of resource deployment away from vulnerable minorities. Any "solution" which suggests that our son is less than a first-class citizen will be resisted vociferously by us in any way which seems appropriate. The painstaking nature of progress towards independence in the distant future should not provide an excuse for making inadequate provision in the immediate present. Education is one very important way of ensuring the optimal quality of life for this sentient human being now.



Circular: "Towards a Programme of Curative Education". 1 April 1983.

INTRODUCTION

The following notes are not intended to be a definitive statement. We are aware that to many professionals involved with Oliver what we have to say may be "old hat" with "these kinds of cases", and some of our suggestions may appear to be unrealistic in terms of practice, or downright erroneous in the light of science. We would be glad to receive correction or further suggestions. Our main concern is that Oliver should be the object of a purposeful, integrated programme of treatment. We hope that this paper will initiate even greater discussion and communication between all those involved.

MEETING

During his times of alertness Oliver displays a high level of waking consciousness, but his periods of awareness have been shorter than the "average" person's, and he seems to drift between different levels of consciousness in a pattern which has not yet been closely analysed. In any case there are almost certainly psychological factors involved as a result of the accident, including the difficulty of evolving a new self-understanding. Oliver is

a child who retreats into real or feigned sleep when faced with apparently insurmountable dilemmas or difficulties; there is every reason to suppose that as the trauma fades and he becomes physically stronger the present trend will continue and his periods of alertness will lengthen. The practical implications of this situation are as follows:

[a] If Oliver's interest is sustained in the context of a caring one to one paedagogic relationship it is likely that the length of learning sessions will very gradually increase.

[b] Oliver should never be stared at, manipulated without explanation, or spoken about in his presence without due deference to his awareness of what is being said.

[c] Eye-contact at close quarters, possibly reinforced by physical contact, may be desirable as long as a "natural" manner can be maintained.

TRUSTING

As in the case of a "normal" child, a trusting relationship with familiar mentors is essential if Oliver is to develop social intercourse. The abilities which we take so much for granted are impaired in his case not only by perceptual difficulties but also by the reinforcement of residual psychological trauma by the oddities in the behaviour of those encountered by him. The situation is akin to E.T. encountering the human race on Hallowe'en! For this reason helpers should avoid "talking down" to him, raising their voices [Oliver is certainly not deaf!] or unnecessarily repeating sentences more than once. As in the case of any "normal" social relationship, humour has an important part to play in removing barriers. A patronising manner will simply erect them.

THINKING

Association of sensory inputs is crucial in the development of cognitive ability, even if no immediate reaction appears to be forthcoming. Guidelines to "effect", however, may be a relaxation of the limbs and rapid eye-movement. Both seem to be indicators of increased mental activity. Simple examples of associative exercises are:

[a] Passive exercises or massage to the accompaniment of music;

[b] Visual stimuli accompanied by spoken or taped narrative or sound effects;

[c] Visual presentations involving textured objects or "speaking" displays such as "Touch and Tell" [Texas Instruments] or puppets;

[d] Clapping or tapping of extremities to music.

Permutations will vary according to the helper's style or temperament.

SEEING

Oliver's hearing and aural comprehension is excellent. His sight is not so good. There appears, however, to be some considerable potential in the development of this sense. Techniques which may be employed in improving his gaze are:

[a] Images which are fixed in a certain point in his field of vision but in which certain elements move. Mobiles are a good example of this, although it is difficult to ascribe meaningful content to them. Glove puppets are better -

especially since movement in this case can be reinforced by spoken commentary.

[b] Images containing simple components which can be scanned, ie. friezes. These should encourage Oliver to perceive images of increasing complexity. Such scanning is all the better if it requires him to employ concurrent head-movement. Friezes which have sequential meaning [similar to cartoon-strips] may contribute towards his re-education in symbolic communication, including written language [which has a major sequential element].

LAUGHING

As already indicated, humour may be fundamental in the development of aural and indeed visual comprehension. It should not be fanciful to suggest that some basic preliminary research is needed into different levels of humour and the degree of mental sophistication involved. Oliver has a ready "sense of humour". The role of incongruity, paradox and word-play in stimulating cognitive development should be explored. [Oliver laughed spontaneously at the following joke: Q.: "Why can't a car play football?" A.: "Because it only has one boot." This indicates that he can understand puns]. "Fun", of course, increases motivation to learn.

SPEAKING

Oliver has developed a simple code of communication. Looking upward means "Yes". Turning the head means "No". Lowering the eyelids may mean "I don't know". Experience shows that Oliver is now so proficient in this code that he can express a range of emphases - the equivalent of spoken intonation. It is imperative that people involved in conversation with him should make every necessary effort to allow him to express preference by use of this code. The procedure is cumbersome but worthwhile. The alternatives are presented and explained to him. He is told that the alternatives will be repeated slowly and he is to "look up" at the alternative which he prefers. This technique means, of course, that helpers must themselves frame the alternatives when Oliver is indicating unhappiness or discomfort by his facial expressions. This can be frustrating for both parties. If for some reason preference is ignored or there is an urgent need which demands attention Oliver will resort to vocal expression - but only as a last resort. In deciding how to respond to such noises two considerations should be borne in mind:

[a] Oliver is not "crying like a baby". This activity may sometimes be unreasonable, but is never irrational.

[b] Oliver could once speak. To make inarticulate sound may be a degrading experience for him. At the moment he is unlikely to make voluntary sounds unless he feels some urgency. Any attempts at speech therapy must take these factors into consideration. Oliver may see vocalisation as "babyish". If his confidence is to be increased speech therapy may have to be conducted in conditions of complete privacy and the purpose of any particular exercise should be explained. It is unlikely that he will "perform" publicly unless his activities in this area have an instantly perceptible meaning to the recipients of his efforts.

CONTROLLING

The ability to exercise some degree of control over one's environment is fundamental to human self-esteem. Any kind of sensory feedback to movement will affect Oliver's confidence and motivation. Furthermore, meaningful feedback to pre-meditated movement will undoubtedly extend the range of his consciousness. Since Oliver's movement is limited, electronic devices are crucial to his development. The technical problems of light-scanned displays, input controls and software need to be tackled vigorously. In this context the role of Possum systems and computers needs to be studied in an imaginative and courageous way. Possible areas of progress with regard to input controls may be:

- [a] Touch-switches operated by head-movement;
- [b] Joystick-mounted buttons operated by Oliver's right thumb;
- [c] Trigger-type mechanisms operated by his right index-finger;
- [d] Fist-held pressure-pads;
- [e] Infra-red beam switches operated by gross leg or arm movements.

Simpler feed-back devices involving buzzers or lights may be developed into meaningful systems of communication. Environmental control systems related to Oliver's needs should be explored. In this respect cues provided by his own conscious or unconscious initiatives – and the degree of frustration registered by him - should be carefully noted.

PLAYING

There is no substitute for the stimulus provided by a peer-group. In placing Oliver in this context careful consideration should be given to the balance between mental and physical capabilities, sex, and age. In this respect, Oliver must be given time and space to express his own preferences.

CHANGING

It is necessary to conclude on an exhortatory note. Pity or mere verbal sympathy [as distinct from active empathy] are of little use to the Medhurst family, even if it has some therapeutic function for the purveyor. Any approach which confers on Oliver less than the dignity of a human being, a spiritual entity capable of infinite progress beyond the physical limitations which are part and parcel of the human condition, will cause Oliver to "switch off" and will make his parents angry. A programme of education should aim, not simply at producing an economically productive worker, or some feeble shadow of a social persona based on a simplistic notion of normality, but a person made in the image of God with the freedom of defining for himself what it means to be fully human. In the face of Man's eternal destiny, the difference between Oliver and anyone who reads these words is infinitesimal. Unfortunately, in the face of society the gap is huge. Like all of us, Oliver must change; but so too must society. A society whose definitions of what it means to be human leads to the virement of resources away from certain human beings must be the object of radical re-appraisal. And the starting-point for change must be those who are in a position to make decisions, but who have not questioned enough their own priorities.

Letter to County Councillor. 8 April 1983

Oliver, our son, sustained a serious head injury on 17 August 1982 and spent seven months or so at Leicester Royal Infirmary. He returned home on 28 March as a disabled person and it is now a matter of urgency to put in hand major adaptations at his place of residence [42a Hobson Road, Leicester]. An application for an improvement grant has been submitted to Leicester City Council. This is being handled by home improvements officer Mr. R. B. [Ext. 6841]. Various alternatives have been discussed with representatives of the County Council Occupational Therapy Dept. - principally Mrs. J. W. [Ext. 7284] but also Mrs. P. K. and Mr. S. K. We have had no personal contact as yet with the Principal Occupational Therapist Mrs. E. Z. A preliminary plan has been prepared by Mr. L. J. C. [864193]

Three issues are currently causing us some concern:-

[a] It has been suggested that a shower be installed as a permanent fixture in the new bathroom. On therapeutic grounds, as well as on the grounds of family convenience and ergonomics, we favour the semi-permanent installation of a Parker bath on a loan basis from the County Council. We have been told [in apparently *ex cathedra* statements] that the County Council would be unwilling to purchase and lend out a Parker bath on grounds of expense. But it should be borne in mind that the installation of an appropriate shower unit on an upper storey would probably involve greater expense to the City Council - and possibly to us personally in view of the ceiling on improvement grants. We believe that the appropriate arrangement should be made with the domestic needs of the disabled person as the sole criterion. We do not wish to fall victim to a financial demarcation dispute between the City and County Councils.

[b] We have been told that we will be expected to defray some of the cost of the adaptations from our own pockets. If this is correct we must know at the earliest possible the expense involved and how our "share" is decided. Clear guidelines should be available regarding local interpretation of the Chronically Sick and Disabled Persons Act.

[c] It has been suggested that it may take a year or more to effect alterations. In view of the physical effort currently involved in caring for our son - which the adaptations are supposedly aimed at alleviating - this time-span would be intolerable.

Please do not hesitate to contact us or any of the above-mentioned officials directly if you require further information. Meanwhile, your assistance in bringing about a satisfactory solution would be greatly appreciated.

Contact Book [Ashfield School]. 11 April 1983.

Don't forget that it is Oliver's left side which appears to be most impaired - although he was previously left-handed. He can move his right thumb up and down [equipment enclosed]. Is this any use? He came home in a very good mood [after an anxious day yesterday] - but retired early!

Contact Book. 12 April 1983.

Slightly worried. After an intensive feeding programme over the holiday he seems to have lost his appetite again and to be losing weight. How is he eating at lunchtime?

Contact Book [Ashfield School]. 13 April 1983.

Owing to the fact that in the last few days Oliver's routine - ie. patterns of sleep, meals, physio. etc. - has gone "haywire" it now seems impossible to predict bowel movements as promised. Your guess is as good as ours!

Contact Book [Ashfield School]. 18 April 1983.

Oliver went to Paul W.'s birthday party on Saturday. His sister Rebekah looked after him while he was there, so we're not sure what he got up to. Later he listened to Paul's sister play the piano and had a "plonk" himself. Listened to a tape-reading of "The Wizard of Oz" yesterday. Oliver hasn't wee'd since yesterday morning so we've left his appliance off this morning. We enclose a couple of pads - I'm afraid he'll have to be changed once or twice during the day. For various reasons we have cancelled a hearing test which Oliver was to have had at the hospital today.

Contact Book [Ashfield School]. 19 April 1983.

Oliver will be attending physio at the Infirmary after school on Tuesdays and Thursdays (except this Thursday when Dr. M. will be coming). I aim to collect him at 3.45 p.m. for an appointment at 4.00 p.m. I am only able to transport him in his "buggy". I suggest that we continue to send him his Avon chair on Tues. and Thurs. together with his collapsed buggy. If Oliver can be transferred to his buggy by 3.30 p.m. ready for collection by me his chair can then be transported home (sans Oliver) in the usual way.

Is this complicated enough for you?!

We forgot to mention that Oliver bought a puppy last Saturday. It's a tricolour (ue. whit, black, brown) Cavalier King Charles Spaniel called "Lottie" ("Charlotte" actually!). She enjoys sitting in Oliver's lap but can be a greedy nuisance when he's eating. She hasn't been toilet-trained yet and keeps chewing things. I enclose a "What-o-Mess" tape - several stories on each side - which you might like to borrow for a while. Oliver has heard the stories once or twice but we haven't discussed them with him.

Contact Book [Ashfield School]. 24 April 1983.

Oliver has had a busy week-end. On Saturday he visited a riding-school with Mrs. Rees and saw some ponies. He's also been out twice in our new red car.

Oliver has sore shoulder-blades. Is there any way we can take pressure off his back?

Contact Book [Ashfield School]. 26 April 1983.

Oliver slept on his tummy last night and will do so tonight. We have a wedge at home but we use it sparingly since Oliver doesn't seem terribly happy on it - partly, I guess, because he gets bored: we haven't yet been able to devise a worthwhile pastime for him in this position!

We are generally concerned about Oliver's posture - he seems to be developing a stiffness in the hips as well as the knees and is clearly spending too much time in a seated position. I suspect that the friction sores on his shoulder-blades may be due to his tendency to slide down (when not in his Avon chair) or sideways into his habitual "banana" shape.

Our own feeling is that the solution is a mobile manual tilt-table normally at 45 degrees but regularly adjusted to shift the centre of gravity. This would solve all of these problems (we think).

I wonder if you could draw the attention of Mrs. M. to these notes today? I would be glad to hear any comments. These matters are of particular urgency in view of the fact that we have had to abandon physio at the Infirmary until a more sensible arrangement can be made. On the positive side, Oliver appeared to enjoy swimming very much, but came home whacked.

N.B. We need:-

- (a) mouth-care sponge-sticks (urgently)
- (b) penile-appliance condoms
- (c) urihesive strips
- (d) Downs catheter drainage-bags (small)

We enclose a "Touch & Tell" toy which Oliver or other children might find usable. Return in due course.

Letter to the City Council Housing Officer [Mr. J. C.]. 27 April 1983.

42A HOBSON ROAD, LEICESTER

You will be aware that as a result of our son being severely disabled by a road traffic accident we have applied to your department for assistance with necessary adaptations to the above residence.

On three separate occasions we have made an appointment to see Mr. R. B., the first being on the 30th March. At the last meeting on 20th April, at which Mrs. J. W. from Social Services, and Mr. A.L.C. - the person responsible for drawing up plans - were present, it became painfully obvious that little or no progress had been made during that month in the consideration of our application. I say "painfully" because of the severe constraints and difficulties under which we are now labouring in the care of our son.

It became apparent during the course of our very brief conversation with Mr. B. that he himself felt unqualified to initiate progress towards a decision without

consultation with senior officers in view of the discretionary element involved. I therefore formally asked him to arrange an appointment for me to meet and discuss the matter with you. I note with regret that you have not responded to my request in the course of the last week.

I therefore reiterate my request for an appointment to discuss the matter with you at your earliest possible convenience. I am confident that I do not need further to impress upon you the urgency of this matter and the cost of delay in human terms.

You will note that I have forwarded a copy of this letter to the local government ombudsman. I am concerned that we should not fall victim to the assumption by either the City Council or the County Council that actions by another Council may relieve them of the responsibility of themselves reaching any kind of adequate decision.

This kind of shuttle appears to have been already initiated in view of Mr. B.'s comments to Mrs. W. at the aforementioned meeting, and the consequent delays are causing us a great deal of concern and inconvenience.

Letter to the Schools Medical Officer [Dr. S]. 27 April 1983.

Thankyou for your important initiative in arranging physiotherapy sessions at the L.R.I. on Tuesdays and Thursdays at 3:45 p.m. Unfortunately, our fears about the difficulties involved in availing ourselves of whatever facilities which may be available to us in the wider context of the community - as we expressed them in the last case conference - have in this respect been fulfilled.

To convey Oliver to the original appointment was impossible without consistent absenteeism from work. It did not seem possible to arrange a worthwhile session beginning after 4:00 p.m. After two attempts to travel from work to Ashfield School to the Leicester Royal Infirmary between 3:15 and 4:00 p.m. it became apparent that this too was impossible. There are no alternatives to this. Although Mrs. Medhurst is available from 1:30 p.m., she cannot drive; neither is she capable of handling Oliver single-handedly. We have therefore had to renege on the agreement.

It was, I must add, particularly frustrating to attempt the conveyance of Oliver to the L.R.I. in the knowledge that there is a well-equipped hospital a stone's-throw from the school!

I do not have to impress upon you the urgency of Oliver's needs and the observable deterioration that cessation of treatment entails. I would be very glad if you would help us to explore the possibilities for an alternative arrangement.

Contact Book [Ashfield School]. 2 May 1983.

Oliver's pressure-sores seem to be clearing up now. We think we have traced the problem to a nylon anti-smother pillow. We had used this to pad Oliver's back when seated because it was slim, and under his face for obvious reasons. Experience has shown that Oliver is strongly allergic to nylon shirts.

Oliver has been having a lot of fun with a tape-recorder and his sister Rebekah who has been giving him crazy interviews. His sister seems to be able to elicit quite a degree of vocal response.

This afternoon we took him to see E.T. at the cinema - and he fell asleep ten minutes after the start and didn't wake up again until we left!

We played with the Atari video-games again to-day. Oliver's favourite is an aerial combat game because he can fire the machine-gun with his thumb.

I shall be ringing Mrs. G. on Tuesday morning to confirm the new arrangements for physio.

Contact Book [Ashfield School]. 3 May 1983.

We have left Oliver's penile appliance off again today. Can you suggest a significant time to set the musical alarm on his watch?

Contact Book [Ashfield School]. 3 May 1983.

Thankyou for the photos - lovely!

Contact Book [Ashfield School]. 11 May 1983.

We have given Oliver a rest today from his penile appliance - so look out for dampness!

Contact Book [Ashfield School]. 15 May 1983.

To-day we went to visit some friends who live in the country. They have a baby called Ben and two dogs called Bracken and Clover. We took Lottie with us and she kept following Bracken around because she's a spaniel too. We visited a place where they fly gliders in the afternoon. We watched an aeroplane tow a glider into the air.

Yesterday we visited the new toy shop where Mummy works - they've moved from the old one in Silver St. to a "new" one in High St. This was after a very boring afternoon in which Oliver watched me mowing the lawn and digging the garden while we played the songs from "Joseph and his Technicolour Dreamcoat" (Oliver knows a few of these songs from his old school).

Oliver went to church last week but he "skipped it" this morning because of the busy day.

Contact Book [Ashfield School]. 16 May 1983.

Read a story to-night from "Mice and Mendelson" in which characters speculated about what the moon is made of - cream cracker or silver shilling? Agreed in the end it was made of ice cream.

Blissymbol flash-cards in Oliver's bag - please return. Are they O.K.?

Letter to Leicester City Housing Dept. (J. C.). 17 May 1983.

42a Hobson Road

Thankyou for your letter dated 12 May 1983.

I very much regret that you have refused my second request to discuss with you the requirements of our son, and the length of time it has taken for you to reach this decision.

I can assure that I do understand your duties as a public servant. In view of this I was very surprised to learn that you regard yourself as in a position to "make a decision". I understood that you were in a position only to make recommendations to duly elected bodies.

Although I am personally concerned by your refusal to gain first-hand information, I will assume that you now regard yourself as being in possession of the facts necessary to make a recommendation that will bear public scrutiny.

In view of your handling of the matter so far I am not entirely convinced of your goodwill towards the disabled community in Leicester. In view of this, I would be very grateful if you would send me a written summary of your recommendations as soon as you can bring yourself to make them so that representations can be made to the appropriate bodies before a decision is reached.

Since your conduct in this matter has broader implications regarding the rights of disabled people. I can assure you that the necessary action will be taken at all levels to ensure your department's policy comes under the closest possible scrutiny in order to facilitate the wide public debate which I shall be initiating should you continue to handle our case in an unsatisfactory manner.

Contact Book [Ashfield School]. 18 May 1983.

We have left Oliver's penile appliance off today.

His face is slightly sore after sleeping on his tummy – yes, we did use a sheepskin!

Contact Book [Ashfield School]. 22 May 1983.

We took Oliver "round town" yesterday, and had afternoon tea in Fenwick's. Then in the evening we went out and left Oliver with Mrs. T., our cleaning lady. He likes her company, and insists we leave him to fall asleep on the sofa while we're out. Today we had grandpa for lunch (as always on a Sunday) and then we went round to his house in the evening - he lives just around the corner.

It's been very quiet at home this week-end – Rebekah's been away visiting a friend.

Contact Book [Ashfield School]. 23 May 1983.

We enclose a facial massager. We chose this one because it had a wide variety of attachments. It seems a bit weak. (Is it the batteries? - we inserted some loose ones which were to hand). We suggest the following additions to Oliver's repertoire:

Grandpa
Television
Tape (recorder)
Story (book)
(Video) game
Cat
Meal: breakfast
 lunch
 tea
Hot - heat - fire
Cold
Sweet
More (adj.)
Wet
Dirty
Position/posture
Change (vb.)
Mrs. Townsend

This is not in priority order!

Contact Book [Ashfield School]. 24 May 1983.

Would you please be good enough to change Oliver's jumper before the end of school so that he's presentable for physio?

Contact Book [Ashfield School]. 31 May 1983.

Thanks in anticipation for the duplicate Blisschart frame.

It has been a chaotic four days in which we haven't done anything in particular except have a stream of visitors - including Oliver's cousin Alexander today who lives in London, and his "uncle" Peter last night who lives in Wales, and Mrs. Townsend on Saturday afternoon and this morning various children.

He did some painting this morning in the garden with his sister and caught the sun on his face. He slept a long time this afternoon and stayed up late this evening - just a little anxious about his stay at school.

Oliver has a new school-bag: the red-and-black striped case. His clothes etc. should be kept in the haversack. We will visit on Thursday afternoon after school. (Oliver has in any case to see Dr. M. at 3.30 p.m. Could someone ring the physio dept. at the Infirmary to tell them he's not coming?).

We shall be very glad of the rest over the next few days - Mum has developed a back-ache and I have a cold! I shall be at home all day Wed. - Fri. Give me a ring (65710) if you need anything for Oliver.

Contact Book [Ashfield School]. 5 June 1983.

Yesterday we took Oliver into town and had tea in Brucciani's. We bought him a racing-driver's crash-helmet to wear in the car!

This morning Oliver went to church and kept making noises during the sermon (I was preaching) - much to Mum's embarrassment!

He can't wear his appliance for a day or two since we've run out of Urihesive strips. A prescription hasn't yet emerged from the G.P. Oliver is now taking two Baclofen tablets at a time (ie. 20 mgs. three times a day).

We would be very grateful indeed if you could arrange to take him for his X-ray at 2.00 p.m. on the 10th.

We haven't mentioned to Oliver yet the possibility of his staying at school next week. We'll break it to him gently towards the end of this week. P.S. Mr. D. enquired about his musical watch. We'll try to remember to put it on him this week.

Contact Book [Ashfield School]. 8 June 1983.

We forgot to say that we have to take Oliver to the Red Cross Medical Aids Centre to-day to look at bathroom aids. Could you possibly keep him until 4.15 p.m. or thereabouts? - and send his Avon chair back on the bus?

We enclose some extra trousers and incontinence appliances (but no Urihesive strips!).



Circular. 9 June 1983. Residential Care

In the course of the last week on several separate occasions it has been suggested by various health service professionals that we as a family might benefit from Oliver being placed in residential care (ie. in a residential school or in a residential unit of a day school) on a permanent or intermittent basis. Since we have not been party to any formal discussions or consultations in which all relevant issues have been raised, we feel that it is necessary to express our own point of view before what we see as a relatively hand-to-mouth approach becomes established by default.

At the outset we would wish to discount the idea of a permanent residential education for our son for the same reasons that we would wish to discount it for our daughter. This is ultimately – or should be ultimately – a question of educational philosophy and other values which it would be fruitless to discuss in this context. In any case we believe that the benefits in terms of treatment which are discussed below would be far outweighed by the emotional and psychological dangers – however attractive the "solution" may appear to a health service which is unable to meet its responsibilities

There are two considerations with regard to intermittent care which should not be confused:-

1. Intermittent care can provide Oliver's parents with a much-needed rest from time to time.

This is certainly true and we are very reassured by the existence of excellent facilities at Ashfield School, and if a permanent placement is made we would very glad to avail ourselves of these facilities from time to time. Unfortunately times of more intense stress are likely to occur during school holidays and we have to explore the possibilities of other institutions such as Charnwood House. This fact leads us to the most important point: that respite care should be provided in the context of a flexible but carefully thought-out programme in which the "disabled family" can identify and express its own needs. The tendency to assume that a handicapped person, or, in the case of a minor, "handicapped parents", are incapable of assessing their own situation and initiating appropriate action leads to increasing dependency which is, we believe, entirely counter-productive. It would seem, therefore, that in the absence of any one person who is continuously and intimately aware of the family's needs, the influence and decision-making capability of parents should be paramount. The challenge inheres in the establishment of streamlined consultative and decision-making procedures in which parents can be fully involved without feeling themselves under pressure.

Emotional pressure on parents may, of course, come about as a result of confusion of aims and criteria in making decisions. It is important in view of this that the needs outlined above should be kept separate from the second consideration which needs to be borne in mind:

2. Residential facilities can provide treatment not available at home.

This consideration is particularly relevant to the current shortfall in the provision of specialised physiotherapy for Oliver. Without deluding ourselves as to the magnitude of the task, and trusting in the effective implementation of measures by the social services, we believe that in all other respects the care provided for us for our son at home is qualitatively better than could be provided within an institution – except, of course, for those particular educational services available within a special school. In view of this fact, specialised physiotherapy is best provided at home or at school. A brief period in residence is undoubtedly a valuable procedure for assessment of Oliver's ongoing needs in this particular area, but should in way be regarded as a substitute for a programme of long-term treatment.

The above-mentioned shortfall is a source of profound concern to us. We are of the considered opinion that Oliver's entire needs are not currently being met. The health service needs, therefore, to consider one, or both, of the following measures:

- (a) Daily physiotherapy on a domiciliary basis;
- (b) Daily physiotherapy at school.

We are compelled at this point to make the general observation that one physiotherapist for a school of the size and nature of Ashfield is totally inadequate. Refusal to face this fact is to collude in the acceptance of an inexorable deterioration in our son's physical condition and an unacceptable burden on the integrity of the member of staff involved.

On a personal note, it is particularly vexatious to us when, as has happened on at least one occasion, discussion of this issue has been fudged by shifting ground to the first observation above. We will not, as a matter of policy rather than of pride, tolerate any suggestion that we are unable to "cope" when it is used to evade this apparently uncomfortable question.

The Community Health Council will, we trust, shortly be sending us a written report on physiotherapy services available. In view of the broader issues involved we shall, if necessary, wish to express concern in the strongest possible terms at all appropriate levels in the community, the health service, and the political system. We certainly have no objection to this document being made more widely available in order to initiate a broader debate. Meanwhile, we hope that the comments contained within it will clear the ground for any further discussions regarding the appropriate institutional support available to us in the continuing care of our child.

Contact Book [Ashfield School]. 9 June 1983.

"The Leicester Trader" may ring the school. They want to run a story on Oliver in connection with a police dog who visited him in hospital. I don't know if you have any contacts with the police, but I'm afraid we'll have to leave it up to you. We have no objection to this kind of publicity (provided we can check the reports for accuracy, but you may not like the intrusion - in which case send them off with a flea in their ear. Any queries ring me on Earl Shilton (93) 45061.

There seems to be rather more movement - probably involuntary - in Oliver's right hand lately ie. extending the fingers. Any suggestions to develop this? (Oliver can apparently now move the little finger on his right hand at will.) Incidentally, do you know if Possum have been contacted for a possible assessment vis-a-vis input controls? If not I'll contact them directly.

I was very interested to hear of the "drawing machine". Is it a mechanical device or something along the lines of a computer "turtle"?

Can you please confirm whether or not Oliver will be in residence next week? - don't worry: we agree to this in principle!

Contact Book [Ashfield School]. 13 June 1983.

Oliver is constipated.

We have sent in some fresh orange juice which we give Oliver first thing in the morning - he wakes up very thirsty.

Contact Book [Ashfield School]. 19 June 1983.

Oliver has eaten like a horse since he came home on Friday. We went into town yesterday - tea in Fenwick's - and we had friends round for tea today. We went to the swing-park this morning. Lottie chased round trying to catch up with us on the roundabout, and Rebekah showed Oliver how useless she is at tennis. He hung upside-down with his legs over a climbing-frame and we went down the slide a couple of times. Unfortunately, Oliver caught the sun; I expect his face will still be sore tomorrow.

We are sending in some "pop-up" books which are marvellous conversation-pieces. You may want to keep them for a week or two.

We hope to get along to the parents' evening on Wednesday.

Circular. 21 June 1983.

**Towards a Programme of Curative Education
Phase II: Some Specific Recommendations**

Physiotherapy

1. That the A.H.A. finance a two-year programme of 500 one-hour sessions of physiotherapy conducted at Oliver's home and/or school (ie. 1 one-hour session per week-day).
2. That the personnel involved should be provided with the necessary support and advice in the planning and implementation of such a programme.

Electronic Communication Aids

1. That the D.H.S.S. provide a portable Possum-type communication-aid for Oliver's specific use at home and school, accompanied by a range of appropriate interfaces.
2. That the D.H.S.S. finance any adaptations to equipment, or the provision of any equipment available from suppliers other than Possum, specific to Oliver's needs.

Education

1. That the L.E.A. provide a teacher on a supply/ home-tutoring basis for three 1 1/2 hour sessions for the duration of the Autumn term 1983 for the specific purpose of instructing Oliver in the Como eye-pointing programme.
2. That the L.E.A. sponsor an in-service training programme in the use of Blissymbolics with a view to providing support for the use of Blissymbols in Oliver's education and in the education of other non-verbal handicapped children.

Finance

1. That in the absence of financial support for the above recommendations from statutory bodies, and these bodies having given an unambiguous declaration of their position, all persons involved in Oliver's rehabilitation lend their support to an appeal for donations addressed to the public for the financing of any or all of these recommendations.
2. That the appeal be launched to span the first anniversary of Oliver's accident (17 August 1983) and his 10th birthday (10 September) - his 9th birthday having been passed in a coma.

Contact Book [Ashfield School]. 21 June 1983.

I'm sorry: owing to the unusual nature of the past week we haven't been able to rehearse Oliver's three new Blissymbols. But we have managed to make out some more flashcards.

Contact Book [Ashfield School]. 23 June 1983.

Thanks for the postcard of the town called "Oliver".

After a "lecture" from his Mum about talking Oliver surprised us both by starting to move his tongue backwards and forwards. With a lot more practice we're sure he'll soon be able to stick his tongue out at you! Despite the anti-social overtones we'd be glad if you would encourage him.

Have a good time at Alton Towers. Phew!

Contact Book [Ashfield School]. 26 June 1983.

Yesterday Lottie was yelled at, smacked, and put in solitary confinement (the garage) for stealing and devouring a stick of Oliver's rock from Alton Towers. She was incriminated by her evident stickiness. Poor old Oliver didn't know whether to laugh or cry - so he did both! This afternoon we went to Abbey Park. We visited Pet's Corner and saw some of the peacocks showing off.

We'll make an inventory of Oliver's equipment before Friday. We were interested in te prone table (ie. when we came on parents' evening). Could we borrow it over the holiday? We have a carpenter friend who might be able to make a Mark II with more leg room. Has his leg-brace been sorted out? Does he wear a collar? etc. etc.

Contact Book [Ashfield School]. 27 June 1983.

We could collect the prone-board etc. at around 4.00 p.m. on Friday - or any day previously in the evening. We have indeed thought over Dr. Chan's "ideas". Subject to a re-assessment when we saw him again on 5th Sept. (2.45 p.m. at the General) we have decided not to use the body-support. We are convinced that there must be a more creative solution. How about sleeping on his left side in a hammock?! Anyway, we'll think further We're sending in for a few days joystick-type control that was made specially for Oliver to experiment with. It plugs into an Atari video-game system like the one at school. Oliver enjoys playing game no. 18 on the "Combat" cartridge. If you have time, could you encourage him to use it? - particularly in pulling it towards the second switch. I'm afraid one of the wires has come adrift from the plug. (I don't know how to solder!). You can see where it goes from the tiny dab of solder; just push the wire in.

P.S. Please congratulate Oliver. The little finger on his right hand is moving even better.



Circular. 1 July 1983.

We hope that this document will be construed as a positive attempt to overcome the first problem. We believe that a frank statement of our own attitudes will remove the obstacles of misunderstanding and clear the ground for a genuine open dialogue in which no individual regards himself as having a monopoly of wisdom. At the same time, we see the proposals set out here as our contribution to the establishment of an integrated programme of curative education which will be genuinely helpful to those who are concerned with Oliver's future.

PROPOSALS

A Basis for Progress

1. As Oliver's parents, our "territory" inheres in his entire being as an emotional, physical, intellectual and spiritual entity. We therefore see our role as crucial in the establishment of an overview. Even if rigorous division of labour hardens into the professional orthodoxy we will never accept any diagnosis and proposed course of treatment which does not take into account other elements in the total picture as adequate. We would wish to see established, therefore, a more streamlined system of consultation in which there would be a freer flow of oral and written information and a frank and open exchange of opinion. 2. We have every reason to believe that Oliver will be early in reaching puberty.

In any child, the pre-adolescent stage, in which mental and physical growth are rapid, and in which processes occur which are unrepeatable, the foundation is laid for the difficult emergence into adulthood. In the adolescent phase the child himself must participate in the evolution of his own destiny - a fact which a parent may view with consternation. While adults may often find themselves helpless during the child's puberty, they have a decisive role to play in nurturing the child's identity and potential in the pre-pubescent phase. We therefore see the next two years between Oliver's tenth and twelfth birthdays, as absolutely crucial to Oliver's future life. We would wish to see established, therefore, an intensive two-year programme – a kind late primary "Headstart" – of education and therapy aimed at directing Oliver's physical and mental growth and equipping him with the basic for him to explore and express his full potential in later life.

Physiotherapy

The enormous degree of physical activity engaged in by the "average" nine-year-old contributes in a major way to the development of a "normal" physique. Such activity is beyond Oliver's reach. Besides facilitating any possible recuperation of muscular function - and the rashness of predictions regarding the extent of Oliver's natural recovery has already been proven - and generally safeguarding his general level of health, specialised physiotherapy (as distinct from "passive movement") is essential in preventing progressive distortions in his posture and physique. If our responsibility to Oliver in this area is not met, then neglect

could have far-reaching consequences to his appearance - a critical factor in his social acceptability - and to his potential for training towards independence at a later stage. The suggestion that we should implement such a programme ourselves is unrealistic in its assessments of the demands upon our time and energy and dismissive of the specialist skills of the qualified and experienced physiotherapist.

We therefore propose:

1. That the A.H.A. finance a two-year programme of specialised physiotherapy consisting of 500 one-hour sessions conducted at Oliver's home and/or school. This means, in effect, one hour-long session per weekday for the next two years.
2. That the personnel involved should have access to the necessary support, advice and consultative procedures in the planning and implementation of such a programme.

Electronic Communication Aids

It has been suggested that "Oliver is not ready for this". We agree. It is precisely because we do not expect him to wake up one morning and find himself capable of using a possum typewriter that a period of initiation and training is essential. Suitable equipment must be acquired soon so that over the next two years Oliver can become highly proficient in the drills and procedures necessary for their operation. He has a great deal to communicate now. By the time he has mastered these procedures he will be able, we hope, to embark on that struggle for self-expression which is so fundamental to the dignity of a human being. The urgency with which children at the primary level are encouraged to acquire literacy skills is entirely applicable to Oliver, however broad our interpretation of "literacy".

We therefore propose:

1. That the D.H.S.S. provide a portable possum-type communication aid for Oliver's specific use at home and school, accompanied by a range of appropriate interfaces.
2. That the D.H.S.S. undertake to make any necessary adaptations to such equipment or to purchase, if necessary, equipment from suppliers other than Possum.

Education

The Blissymbolic system provides an important framework for Oliver's cognitive development and, at a more mundane level, day-to-day communication. Even if Oliver is able to develop efficient usage of electronic aids, the flexibility and autonomy of eye-pointing techniques means that they will continue to be the basis for most of his social interaction. With a great deal of foresight and enthusiasm Oliver's speech therapist has already initiated a learning

programme; but other demands on the therapist's time and the importance of the system to Oliver's overall education make extra input essential.

We therefore propose:

1. That the L.E.A. provide extra teaching-support for a limited period (at least one term) for the implementation of an eye-pointing programme related to the broadening of Oliver's Blissymbol vocabulary under the supervision of the speech therapist. It may be desirable to back up such support by the provision of a modest programme of in-service training for the teacher involved.
2. That the L.E.A. purchase and provide on a loan basis the range of equipment necessary for the implementation of such a programme.

Finance

If the relevant statutory bodies are unwilling to make the necessary financial outlay to support the proposed two-year intensive programme we intend to seek public support. We believe that an appeal is best initiated during the period 17th August - 10th September 1983 to be concluded at Christmas 1983.

(17th August 1983 is the first anniversary of Oliver's accident. 10th September 1983 is the date of Oliver's tenth birthday. His ninth birthday was spent in a coma.) The funds would be administered by a trust and directed to the areas of unmet need. Since any such appeal would inevitably involve the co-operation of the media it will be difficult to control its impact on those institutions directly involved in Oliver's welfare. We hope that such institutions will nevertheless view such an appeal sympathetically and regard it positively as an attempt to supplement the excellent services which they are providing. In particular, we hope that Ashfield School will be willing to accept par contributions from individuals or corporations and to tolerate the concomitant publicity which may be desired by the instigators for other than altruistic motives!

In order for such an appeal to be possible it is necessary for us to receive a definite response to our proposals by the end of July 1983. We realise that the Health Service will be wary of any adverse publicity that may accrue to a categoric refusal of services, but we hope that the individuals involved will put Oliver's welfare before their own real or imagined "image".

Conclusion

We conclude our proposals with a plea for understanding. Although we are absolutely committed to caring for our son at home, in the belief that the optimal development of his potential can only come about within the context of a strong and caring family, we do not underestimate the difficulties involved in marshalling the appropriate support, nor do we denigrate the work which has already been done. We particularly appreciate the care and creativity displayed by some professionals in taking initiatives which have entailed extra work for them. Having said this, however, we beg those in a position to make decisions to consider the following facts:-

1. There is a limit to our time and energy. Even if we had the expertise it is difficult, considering the current demands on our domestic routine, to set aside a "slot" for any particular task beyond those essential in the parental care of a child, and to find the energy necessary to sustain extra input.
2. The health of the family as a whole is essential to Oliver's well-being. A routine which jeopardised our own physical health and led to the neglect of our daughter would ultimately be detrimental to Oliver.
3. Some types of input can only be effectively made with a degree of objectivity and detachment which parents in any circumstances would find it difficult to sustain. Being a parent has its own satisfactions, but the role is sometimes incompatible with techniques which must be used to get results.

We have the will to overcome these difficulties. We are asking for a comparable measure of goodwill from the caring services - both for the sake of Oliver, and for the sake of future victims of traumatic brain-injury for whom provision may still be regarded as on its infancy.

Contact Book [Ashfield School]. 1 July 1983.

Inventory:-

Avon chair
Tray
Joystick and bell
Custom joystick
Four "pop-up" books
Prone-board (loan)

I will collect at 4.00 p.m.

Letter to the Chairman of the Area Health Authority (Prof. A. R. B.). 7 July 1983.

We are taking the unusual step of writing to in order to clarify for ourselves the overall strategy in the treatment of our son during the next two years. This overture is in no way meant as an attack on the professional integrity of anyone currently engaged in his treatment. But we feel that, owing to the difficulties of prognosis in cases of traumatic brain injury, and to the scarcity of resources for the treatment of long-term patients living at home, opportunities for progress, however uncertain, may be overlooked.

As laypersons without medical training it is difficult for us to moot proposals with a trustworthy objectivity. But as the child's parents we entertain an overview of his total welfare which emboldens us to suggest provision which will, we believe, "block in" elements within a total strategy for achieving his optimal well-being. We are aware of the financial and administrative pressures which make standardisation of treatment necessary, but you will be aware that the complexities involved in meeting the needs of a brain-damaged person make

individual programmes imperative. We are therefore seeking to use what flexibility there may be within the health service to initiate discussion as to how far our son's potential can be explored and developed.

We are currently witnessing a deterioration in our son's posture which we will not accept as inexorable. Leaving aside the questionable functional capability of his limbs, we believe that his appearance is a crucial factor in his future social acceptability. We are certain that you do not need to be reminded of the importance of "cosmetic" factors in a patient's personal and social well-being. At the same time, we feel that our son should be maintained in a state of optimal physical fitness in order to maximise the potential natural recovery of limb-function. Regular physiotherapy is therefore essential. At the moment, owing to what we perceive as a shortfall in provision at Ashfield School, Oliver is not receiving regular treatment at school. We are also uncertain as to how far the two 45-minute sessions which he is currently receiving at Leicester Royal Infirmary can be, or will be, sustained. We believe that one hour of physiotherapy on each weekday sustained over a two-year period is the minimum requirement for this particular patient. If a doctor is willing to state in positive terms that this is not a minimum requirement we would then re-consider our intention to question the current shortfall at all levels.

Our next concern is Oliver's potential for communication. We understand that Dr. Moore has initiated the process of application for a communication-aid and that our son is likely to be assessed for a P.O.S.S.U.M. typewriter in the near future. Once again, however, we find it difficult to see how the standardised provision - if and when it materialises - can be adequate to our child's needs in this area. We feel that a customised "package" needs to be assembled which provides a range of input controls relating to a system which utilises the most recent advances in microelectronics now available from a variety of suppliers. This challenge must be met sooner or later. We are asking the District to start here.

We realise that it is impossible to separate medical, social and educational provision. We hope that this will not, however, lead to demarcation of responsibility disputes between the caring services. You can be assured that we are making other, discrete demands on the Social Services and the Education Service. We feel that the issues outlined above fall squarely on the shoulders of the Health Service.

We must conclude by saying that if resources or services are not available via the N.H.S. to meet what we see as the minimum requirements outlined above, we must reluctantly explore other sources of help. In order to facilitate this, a categoric refusal of provision could be helpful. Since we hope to embark on a two-year programme in the autumn, in order to take advantage of our child's current developmental stage, it would be very useful if you could assist us in clarifying the picture in the next month.

Assuring you of our goodwill and active co-operation at all times . . .

**Letter to the Adviser to the County Council on Special Educational Needs
(Mrs. C. E. S.). 7 July 1983.**

Thankyou for your letter of 21 April 1983 and its very positive response to our pamphlet "Towards a Programme of Curative Education". We found a great deal of encouragement in your offer to explore ways in which the local authority could improve the resourcing of our son's education.

As you are aware, as a result of his accident Oliver can no longer talk. His receptive capabilities, however, appear to be largely unimpaired. His eyesight, although it has improved considerably over the last few months is still affected in ways in which it is difficult to assess, but it seems likely that he would experience difficulty in using a written system, like the phonetic alphabet, which required rapid absorption of small, sequential characters.

In view of these problems, we believe that the Blissymbolic system offers the best vehicle for the continuation of Oliver's education. It is, however, an onerous task for a child to rapidly reach mastery of a system "from scratch" to the degree required to embark on a meaningful language-enrichment programme. A modest attempt has been made to begin teaching the system by Oliver's speech therapist, but the limited sessions available, and the other demands on time within those sessions, together with the very limited teaching materials at her disposal, makes it extremely unlikely that progress commensurate with Oliver's learning capability will be sustained.

We realise that the extent to which extra teaching-help may be available for a Blissymbolics learning-programme is potentially a contentious issue, but we are eager to know whether the County has invested, or is willing to invest, in materials and equipment specific to the Blissymbolic system.

We would be very grateful if you would furnish us with any information regarding the availability of such materials on a loan basis in this Authority. We appreciate that we may have to purchase such materials ourselves, but with there being so many demands on our financial resources at this time, we feel obliged to proceed with this enquiry.

We look forward to your continued support and active sympathy in the difficult months ahead as we seek to establish the best possible individualised learning-programme for our child.

Letter to Occupational Therapist (Mrs. M. M.). 8 July 1983.

You will be aware that Dr. C. saw Oliver in the middle of June and will be seeing him at the beginning of September. As a result of his "advice" we have decided not to use a support jacket. This decision will be reviewed in September pending the result of a further X-ray.

We are now at the stage where a satisfactory seating-arrangement for Oliver is a matter of urgency. Please let us know if you need any further co-operation from us in moving swiftly towards the provision of a moulded seat. You will be aware

that our solution to the problem of Oliver's vehicular transportation is largely dependent on the finished product.

Letter to the Occupational Therapist, Social Services (Mrs. J. W.). 8 July 1983.

Thankyou for your help so far; we look forward to further liaison with you regarding the programming of the adaptation-works to our house. As you know, we are hoping to move towards a long-term solution to Oliver's mobility problems. Towards this end we have purchased a vehicle which can accommodate a wheelchair. Until his individual conveyance problems are solved vis-a-vis an appropriate wheelchair, adaptations to the vehicle itself are not a matter of urgency. A solution to the problem of loading and unloading of Oliver in a wheelchair is, however a matter of extreme urgency. Our son is growing at such a rate that it is now no longer possible for one person to lift him without risking physical injury. This severely reduces his mobility.

We would therefore be very glad if your department would consider lending us a portable jack-hoist for loading and unloading a wheelchair. The purchase of the vehicle is a considerable drain on our finances; we simply cannot afford to deploy more of our thinly-stretched resources in this area.

We would be very grateful if you would advise us of the necessary procedures in submitting a formal application.

Contact Book [Ashfield School]. 12 July 1983.

Oliver has urinated into a bottle three nights running at bedtime.

Letter to the Principal Educational Psychologist [G. T.]. 14 July 1983.

Thankyou for your letter of the 13 July. We found our last meeting with you very useful and for this reason we look forward to seeing you again on 20 July at 3.15 p.m.

Your letter seems to suggest that you are only willing to share information with us as a result of the obligations imposed upon you by the 1981 Education Act and the legal framework provided by it. It would be helpful if you would confirm this in writing before our meeting so that our attempts to establish an open partnership with professionals beyond the terms of the Act can be seen to be, as we suspected, quite futile.

Yet again, as we seek to express our views, we are forced to state that we are in no way conducting an attack on anyone's professional integrity. We have no doubt whatsoever that "a lot of people are working very hard in Oliver's interests".

Please feel free to use our last letter in whatever way you think best in the furtherance of Oliver's educational interests.

**Letter to the Assistant Director of Education - Special Needs [Mr. D. E. R..
20 July 1983.]**

I am writing to ask for a full assessment (under Section 5 of the Education Act 1981) on my son Oliver, as is my right under Section 9 of the new Act. My son is currently receiving special educational treatment at Ashfield School, Leicester.

We trust that the process of compiling information for a formal statement of Oliver's special educational needs can begin forthwith. Mrs. Medhurst and myself look forward to hearing from you as soon as possible.

Circular to all representatives of the news media. August 1983.

THE HEADSTART FOR OLIVER PROGRAMME
(H.O.P.E.)

and

THE OLIVER MEDHURST BIRTHDAY APPEAL

Launch date: 17 August 1983. This is the first anniversary of Oliver's accident.

Oliver's situation has already received some media-coverage during the past year. Radio Leicester gathered together some of Oliver's friends to make a broadcast aimed at bringing him out of his coma. "The Leicester Mercury" ran a story about the impact of a police dog on his recovery. "The Leicester Trader" reported a farewell visit on the dog's retirement.

These stories generated a huge amount of interest. We received very many enquiries about Oliver's progress from complete strangers. These enquiries have convinced us of the enormous concern on the part of the public about his situation and have encouraged us to seek wider support.

We believe that Leicester would like to hear more about Oliver. We are willing to supply any information you require. In return, we are asking you to help us give details of the Appeal to the public at large. We are convinced that many people wish to help and would welcome the Appeal as an opportunity to make their own contribution. We hope therefore that you will send a representative to a PRESS CONFERENCE on Monday 15th August at the offices of the Leicester Diocesan Board for Social Responsibility: 278 East Park Road, Leicester (Room 6) at 2.30 p.m. Tea will be available. Oliver, his parents, his sister and the family dog will be at your disposal.

Please help us to get our message across. We are certain that the people of Leicester want to hear it.

Letter to the Director of Education [Mr. F.]. 12 August 1983.

Thankyou for your letter of 3rd August 1983 and the news of your proposal to assess our son's educational needs with a view to the possibility of making a Statement in accordance with the 1981 Education Act. We confirm that we are in agreement with such an assessment being made.

If you decide to go ahead with a full assessment we look forward to receiving a formal notification of this decision as soon as possible. We trust that you will then forward to us details of a named officer to whom we may go for further information, in accordance with Section 5 (3) of the Act.

The specification of a period of 29 days for comment in your letter of the 3rd August, however, suggests that this is to be regarded as formal notice of your intention to make an assessment. If this is the case, then we would be grateful if you would supply us with the name of an officer forthwith so that we can make the best possible use of the remainder of the specified period, in accordance with S. 5 (3) mentioned above. In particular, we would be grateful if you or the named officer would supply written answers to the following questions within the specified period:-

1. Do any reports already exist about Oliver? If so, can we have copies?
2. What advice does the authority intend to seek, and from whom?
3. Will those giving advice be provided with checklist contained in Circular 1/83, and what is the authority's attitude towards this checklist as a basis for advice?
4. What examinations will be required, for what purpose, by whom and where?
5. Will there be any case conferences and if so will we be informed and invited to attend?

In addition to a written reply to the above questions, we would be grateful if arrangements could be made for us to meet with the named officer within the specified period for a discussion about the availability of appropriate educational provision for our son within the authority, in accordance with EA 1980 S. 8, Education (School Information) Regulations 1981 and Circular 1/83 para 20.

In conclusion, and on a less formal note, we wish to express our hope, that it will be possible to build up a relationship of complete trust with those who are concerned with making decisions which affect Oliver's future, and that this will enable us to fulfil the spirit as well as the letter of the law.

Contact Book [Ashfield School]. 15 August 1983.

Oliver is now completely "dry", even to the extent of being reluctant to use a penile appliance for convenience on outings. (He does, however, still wet when asleep - although he does "save" some for the morning). He urinates round about 10 a.m. and 1 - 2 p.m. into a bottle in a supine position. He indicates his desire to "wee" by a low moan which we're sure you'll soon pick up.

We went swimming last week at the Holiday Inn (Oliver is a member). His lack of control over self-immersion in the cold water makes him tense up, but for some reason he seemed a lot looser after a session in the sauna!

Oliver went to the Red Cross play-scheme twice, but his inability to participate in any activity (apart, perhaps, from playing with a remote switch-operated toy car) has convinced us even more of the urgency of developing input controls. Dr. M. tells us that Dr. M.-L. will be coming to assess Oliver – for POSSUM – in September. I have, incidentally, ordered some Blissymbol software for an Apple II computer.

A dentist (Mr. C.) has had a look at Oliver's teeth and will be fitting a brace in September.



Public Leaflet. 17 August 1983.

THE OLIVER MEDHURST BIRTHDAY APPEAL

Who is Oliver?

In August 1981 Oliver Medhurst was a normal eight-year-old boy looking forward to his ninth birthday and enjoying the summer holiday. Then disaster struck, and a month later Oliver spent his birthday in a deep coma.

Every parent's nightmare had come true. On his way back home from the corner shop Oliver ran out into the road and was struck head-on by a car. Witnesses say the driver was not to blame. His parents dashed to the scene to find their son gasping for life. The family was rushed to the Infirmary where it was found that, besides breaking both his legs, Oliver had sustained a serious head injury.

During the following weeks in Intensive Care the staff at Leicester Royal Infirmary were brilliantly successful in their struggle to save his life, but could not prevent permanent brain damage. Surgery at Leicester and later at Derby helped to minimise it, but no-one could be certain how long the coma would last

Three months later, as parents and friends lived through the agony of doubt and fear at his bedside, Oliver began to emerge from his twilight world. But his problems were only just beginning.

The Challenge

Thanks to the constant and devoted care of hospital staff and friends Oliver began to return to the world he had so nearly left for ever. Moments of joy relieved the seemingly unending darkness - like when a visiting police dog jumped on his bed, barked, and Oliver opened his eyes wide in boyish wonder; or when the shared reminiscences of his mum and dad were acknowledged by a smile - the first they had seen for months.

From that moment on, his parents knew that any attempt at stimulation, any contact with the real world, any therapy - no matter how unusual - was worthwhile. As friends prayed throughout the County, their prayers seemed to be being answered. But it also became clear that God had set a task for everyone who cared - a task that demanded all the skill and patience of a midwife at a unique rebirth

What makes Oliver special?

Even when Oliver had "woken up", it was clear that he could not move or talk. In the early stages he could not even swallow. Gradually, he learned to take, chew and swallow solid food. Painstakingly he developed movement in his head and eyes. It became apparent that his left side was more affected than his right - as though he had suffered a giant "stroke". With the strength and

determination that only a child has, his struggle to move an arm or finger continues - every week a millimetre more. He refuses to be "written off".

Most surprisingly of all, it has become obvious that Oliver understands everything that is said to him. He listens to stories. He enjoys music. He answers "Yes" by looking up and "No" by turning his head. He cries when something isn't "fair". He laughs at jokes. We thank God that his sense of humour is intact. The "old" Oliver is still very much with us. He still has the same likes and dislikes. He can still be naughty by refusing to eat his dinner, still win hearts by his melting smile and rolling eyes. Oliver is still a person. Like a secret treasure in broken but salvaged box his personality is still there to be cherished.

But we are left with a tantalising question which only you can help us to answer. How much progress can Oliver make before the vigour of childhood leaves him? And what sacrifices can we demand of the community at large to give Oliver that boost he now so urgently needs? Can you help us face this challenge?

THE HEADSTART FOR OLIVER PROGRAMME (H.O.P.E.)

Our aim is to provide Oliver with an intensive programme of training and therapy over the next two years. If he is to develop healthily in body and mind, he must be treated by experts and he must be given apparatus and the skills to use it. There are no "miracle cures". Oliver himself must do the work. It will be a long, hard slog. But we hope that with the right treatment and equipment Oliver, by the time he has reached his teens, will be able to begin the struggle towards independence.

The National Health Service has saved Oliver's life and set him on the road to recovery. But now that he has left hospital the few resources that the health service can provide are stretched to their limit. We need cash - to pay physiotherapists and teachers to pay for the use of facilities, to pay for equipment and to pay for special adaptations so that Oliver can use it. H.O.P.E. will be based on a three-pronged attack on Oliver's disabilities:

1. MOVEMENT

Oliver is effectively paralysed. He cannot do anything for himself. To prevent deformities as he grows, others must exercise him. It is back-breaking work, made even more urgent by the need to keep his limbs supple just in case he develops more movement. This is always possible as his brain heals and makes new circuits to by-pass damaged areas. But the wrong sort of exercise might do more harm than good. So we must pay physiotherapists to give skilled treatment and advise volunteers.

2. COMMUNICATION

Oliver cannot talk and he cannot write. And yet, before the accident, he had an above-average reading age. We must unlock the reading-skills gained in the last

nine years and help him to develop more. You may have heard of P.O.S.S.U.M. (Patient-Operated Selector Control Mechanisms). The technology to help Oliver does exist, but it is expensive. And to help him to gain access to the world of electronics and micro-computers, special controls must be made to overcome Oliver's disabilities. So we must pay experts to build the right equipment.

3. LANGUAGE

"Speech plays a vital part in the organisation of complex forms of mental activity". This quote from an eminent psychologist can be put in plain English: if Oliver's speech does not develop, neither will his thinking. Although Oliver is beginning to make sounds, he will not be able to speak for a long, long time - if ever. Yet he has plenty to say. Blissymbols can help him to express day-to-day needs and be educated. The quicker Oliver can build up his Blissymbol vocabulary, the quicker he will progress mentally. So we must pay for extra tuition and teaching materials.

Oliver's parents are committed to caring for him at home, in a normal family atmosphere. There are some things which money cannot buy. But the stresses and strains of bringing up a severely handicapped child are enormous. Your contribution will help both Oliver and his family to survive and to flourish. Faith moves mountains. Let us have faith, not only in the cash, but the care and concern of the people of Leicester.

HELPING OLIVER: A SHARED ADVENTURE

The world is plentiful in suffering and scarce in resources to deal with it. Those who care about others and want to help them out in their troubles are faced with a dilemma: whom should they choose to help? Where will their contribution have the most impact? How will a donation get the most results?

In deciding whether or not to support H.O.P.E. We ask you to consider the following points:

1. Life is more than survival. The community as a whole, through the National Health Service, has enabled Oliver to survive. We are now asking you, by supporting our two-year programme, to improve his quality of life. This is usually a matter of choice for each individual. We hope that, with your help, Oliver too will have a choice as he overcomes his handicaps.
2. Oliver is in that rare category of children who suffered brain-damage in later childhood. We have nine years of "normal" childhood to build on, in which he learned to talk, read, and do things which other brain-damaged children cannot do. Oliver is therefore in a unique position to help explore ways in which we can overcome major handicaps.
3. Unlike in the U.S.A., management of traumatic brain-injury in this country is still in its infancy. By helping us to work out and implement a programme of treatment you are helping us to show what can be done with other accident

survivors. By supporting us, you may also be indirectly supporting other relatives in their struggle to get the best treatment for those they love.

There are many things which Oliver needs which money cannot buy. The new challenge facing him would be impossible without a caring family and a circle of friends in which, despite his strange disabilities, he can find acceptance as a child with the same hopes and fears as other children. But cash is important.

SHOW YOUR CONCERN BY GIVING US A DONATION TO HELP US PUT OUR CARE INTO ACTION.

Public Leaflet. 17th August 1985

THE OLIVER HOUSE PROJECT. CURA: The Co-operative Union for Rehabilitation and Advocacy

CURA is a Midlands based association of multiply-handicapped children and young people, together with their families. It aims to provide support to its members, for as long as is necessary, in their individual and distinctive quest for educational and therapeutic progress and optimal quality of life.

In particular, CURA aims to:

- disseminate information about the implications — physical, intellectual, emotional, social and spiritual — of the disabilities of members in order to promote greater care and concern among the public;
- make representations regarding individual needs to community care professionals and administrators;
- acquire and deploy staff for the care, education and therapy of member in order to ease the burden on their families;
- make available equipment and resources necessary for rehabilitation and independence.

Central to CURA's philosophy is the idea that members and their families should decide their own individual priorities and shape their own distinctive programmes for rehabilitation. The ultimate aim is to establish a life-style as independent as possible of the constraints caused by the social and economic, as well as physical, aspects of handicap. It recognises that curative education or holistic therapy is a lifelong process of meeting co-operatively the unique special needs of each severely disabled person.

THE OLIVER HOUSE PROJECT aims in the first instance to set up a therapeutic community of two or three young people in accordance with the ideals of CURA. The Project is named after Oliver Medhurst, the childhood victim of a road accident, whose urgent needs have inspired the initial planning. Its main aim is to purchase and equip premises suitable to the needs of the severely handicapped, situated within the wider community, and providing an environment in which care may be undertaken by professionals, volunteers, and the friends and families of the disabled.

WHY?

Parents of severely multiply-handicapped children have particular difficulties in facing the future. Once the support provided by statutory education has come to an end, the handicapped young person can either be placed in an institution, or continue to be cared-for by ageing parents who must inevitably relinquish their duties as their powers fail. Long-stay hospitals must be subject to strict

routine, be under constant financial pressure to accept a wide variety of patients, and be compelled frequently to ignore the distinctive needs of any particular individual or sub-group.

WHAT?

THE OLIVER HOUSE PROJECT aims to overcome these problems by providing:

- **premises** totally adapted to the needs of the severely disabled occupants, using technology to reduce the labour-intensiveness of care and to facilitate independence wherever possible;
- **facilities** for live-in or visiting care staff;
- **an environment** in which relatives, friends and volunteers are encouraged to contribute to care support;
- **a home** integrated with the wider community and accessible to public services and amenities;
- **an open, supportive community** which provides optimal opportunities for social interaction and the economical deployment of educational and therapeutic support;
- **independence** from impersonal bureaucracies in the context of an association dedicated to the special needs of the community members.

HOW?

The Project is sponsored by CURA (The Co-operative Union for Rehabilitation and Advocacy) and is financially dependent on voluntary contributions from the public.

A Board of Trustees has general oversight of CURA and THE OLIVER HOUSE PROJECT and carries legal responsibility.

A General Council is responsible for shaping and implementing the policies of CURA.

A Management Committee is responsible for the running of THE OLIVER HOUSE PROJECT.

TARGET DATE FOR OPENING: 1990

▪ END OF PART 1 ▪